

# VISION

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## **Christchurch Quake, 12:51pm 22nd February, 2011**

To the good people of Christchurch, we care! We are right behind you. To those who have lost loved ones, we pray for you and your family. To those who have lost homes, again we pray for you. The loss of employment, of schools and of infrastructure etc. YET Christchurch goes on. The spirit of the Red and Black will survive. To those who are left behind, Kia Kaha, know we care and are here.....

To our PVI family, this is a time of valuing family, looking after each other. We understand some have left Christchurch to live in a safer area for the time being. Please contact us so we can rest knowing you are okay etc.... **0800 312 019 or paul@pvi.org.nz**



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# Christchurch....

Dear Parents,

**Christchurch Earthquake—Information for Families:**  
by [chrissiebutler](#) on 28/02/2011

All BLENZ staff offer their best wishes and support to the Christchurch students and families with whom we are dealing so much following last week's earthquake. Our thoughts are also very much with our BLENZ Christchurch staff.

- The Christchurch Visual Resource Centre is closed for the immediate future and is unable to offer a service right now.
- If there are any queries please contact the Coordinator for Visual Resource Centres, Steve Bellamy on **09 2683214** Mobile **021 020 60849**.
- If there is any support needed for student equipment Santa and Maurice Sloane from Humanware **03 384 4555** advise that they are operating and are available to provide support.
- For any parents who are moving their children who are blind or low vision to another region temporarily, or principals receiving these students, please contact the local Visual Resource Centre for support. Contact details if needed can be provided by Steve Bellamy on 09 2683214 Mobile 021 020 60849.

## USEFUL SITES

Canterbury earthquake official site –

[canterburyearthquake.org.nz/](http://canterburyearthquake.org.nz/)

Crowd-sourced information – [eq.org.nz/](http://eq.org.nz/)

Civil Defence – [www.civildefence.govt.nz/](http://www.civildefence.govt.nz/)

Twitter – <http://twitter.com/#eqnz>

## Our story: From a ChCh PVI Parent

It was very terrifying. I was at work on the second storey opposite Riccarton Mall and struggled to get out of the building with flying furniture.

Distressed and shaking in the carpark I tried desperately to reach Emma, Holly & Kerry by cellphone but was unable due to lack of access because of overload of the network. Everyone was trying frantically to get to loved ones and the roads were all damaged and traffic was backed up. I finally got 5 minutes from home to finally hear from Kerry that he had collected Holly.

Emma was at home all alone and was very traumatised as the furniture in the house collapsed around her. She could not get out as the front door jammed and Kerry had to force it open to get her out. The neighbour said she could hear her screaming.

The road has a large crack which has meant this crack has gone right through our house causing quite a bit of damage to tile floors, walls and ceilings. The driveway and patios have pulled away from the house and the front of the house (kitchen, dining, lounge and entry) are on a down hill slope. This means we will have to rebuild. But it is only a house. On Friday we got back water and power.

The Royal Foundation of the Blind have rung us several times to check how we are doing which has been wonderful. Gendy Ritzma spoke to both the girls and the Foundation has put \$20 credit on each of their cellphones so they can stay in contact with us as much as possible. Their kindness during this time has been really appreciated by our family.

We feel blessed that we have come through this as so many other people are suffering much worse. Lives have been lost and people are severely injured or missing.

Christchurch will never be the same again.

Before this happened on February the 14th (Valentine's Day), we did have better news. Kerry after 12 years finally proposed to me....!!! I did say to him the longer it took the bigger the ring. So you can imagine if you know me well ..how lovely that ring would be, that I chose on the weekend before the quake. Unfortunately, I do have to wait longer as it was being altered to fit my tiny finger and is inside the damaged Palms Mall in Shirley at the moment. So now I have to wait ...longer !!! How frustrating. ....(Hmmmmm....Mrs D...does that sound good ???)

We now have to focus on our family and be grateful for everything and everybody we hold dear. This year started positively and our spirits will not be broken.

Love to you all

Michelle, Kerry, Holly and Emma

## Wanting to do something for the People of Christchurch?

**Come to a 'House Concert' at the Seckers,  
13 Brougham Street, South Nelson, Saturday,  
March 26th at 7.00pm.**

Featuring:

*Steve Low, Jenny Daniell, Mark Steyn, Helen Tippler  
and Adrian Secker*

Tickets \$20 - may sound a lot - but 100% goes to Chch quake fund and our Southern Neighbours are hurting. Bring drinks, a plate and positive energy. Circulate email as you wish.

RSVP to [adrian.secker@gmail.com](mailto:adrian.secker@gmail.com) or 03 5484840

## YOU KNOW YOU ARE IN CHCH WHEN...

You use the term "liquefaction" in casual conversation.

Digging a hole and pooping in your garden is no longer weird

Your mayor describes the city as munted

Driving on the wrong side of road is normal

You see tanks round town and curfew as a good thing

You are always noting what you are under

Due to frequent aftershocks, you sleep like a baby-- wake every 10 minutes and sh\*t yourself

**From a ChCh PVI parent....**



## Christchurch....

Life is very bizarre down here at present. It seems a cruel twist of fate that we are only 3 hours drive away, and for us, life is carrying on pretty much as normal, while Christchurch is devastated. We had a couple of days of milk and bread rationing / unavailability, some gaps in the supermarket shelves, and some products being brought out by panic buyers, (including petrol), but that was about it. Much of the stock for Oamaru's supermarkets comes via ChCh, so there will be gaps for a wee while. But running into people from ChCh in the supermarkets buying up food to take back in the days after the shake, was sobering. They stood out very clearly,...they were the dust-covered, white, shaky ones, with red eyes, and trembling limbs, that sometimes had tears running down their faces that they weren't even aware of. Lots of hugs were exchanged by complete strangers.

And the kind side of people came to the fore,... in the supermarket the bread shelves were emptied as soon as anything came in, but shoppers would come up and ask if you needed the loaf they had in their trolley more than they did. (normally if there was only 1 loaf left, you could lose your hand reaching for it.!!)

The town is full of people who have abandoned ChCh and are staying down here for a while in the motor camp, motels, or with relations and friends, or complete strangers. They had no clothes, no wallet or cash cards, handbags, .....nothing but what they left in when they ran. Our SPCA is full of ChCh pets being cared for, and many people have taken in some for respite care in their homes. (many people bundled themselves and their pets into their cars and drove out of the city, only to find they cannot have their pets where they are staying.)

There are several drop-off points in town where you can drop off goods to be taken up. We have moved past the food, water, blankets and clothing time, and are now into the "spare home-ware, appliances, bbqs, " etc etc. When the quake tipped everything out of peoples cupboards onto the floor in a big heap, things broke. They now have no plates or cups,...silly stuff like that. Toasters, jugs, blenders, and things. I had never really thought about things like that, until my friend said she had only 2 plates and 3 mugs left of all her crockery. Many Oamaruvians have had the biggest clear-out of surplus goodies the they have ever had. But there is brand-new things in there too. And this weekend a local bus company is arranging several buses to take people to ChCh early in the morning, and home in the evening, BYO shovel and spade, for the clean-up effort.

Gosh NZdrs pull together when we need to, don't we. A friend of mine was on the 8th floor of a building in the CBD ,....she got out, but had to crawl over dead bodies. Her home is trashed, no power, water, or sewerage, and not likely to get any for a few weeks. She has abandoned ship. My brothers family are in Rolleston, happily they are still able to stay in their home for now, and have water power and sewerage. Their roof is no longer being held up properly as some of the roof bearers broke, so everytime there is an aftershock they think "is it going to come down on our heads ??" The strain in their voices is incredible.

Another friend of mine went to ChCh to collect her daughter, the 3 hr trip took over 6 1/2 hrs, and the last part they had to leave the car and wade thru knee-deep silt, mud, sewerage, and liquefaction, to get to her house. She has cleaned out her car 3 times since, and said to me the other day it still really stunk inside it. I told her she was probably more sensitive to it, and she told me to stick my head in and sniff. So I did. And then I threw up in the gutter. It was the rankest thing my nose has ever encountered, and I have a fairly strong stomach. Apparently it smell like that everywhere up there.

Down this way, almost every single person has either family, or knows someone in Christchurch, and every day you hear a friend say they have a loved one still missing, or homeless, or jobless. It has affected most of us in ways we never dreamt, and although it is hard to imagine a good side to all the tragedy, maybe we will all come out better people as a result, a bit more compassionate, a bit more caring , a bit more willing to share, and reach out a helping hand.

It is heartening to hear how the consumer groups and the RNZFB have all pulled together to keep in touch with everyone. It must be wonderful for blind, vision impaired, and deaf blind people to have someone reach out and make sure they are okay, as they must feel even more vulnerable than the rest of the population does.

Anyway, thanks for the update and info

Pat



## PVI NZ Parent model respected internationally

### **ICEVI and WBU London Dec 2nd, 3rd, 4th, and the RNIB visit 6th and 7th London.**

As a result of the work PVI has been involved with work in the South Pacific (Fiji) and having been seconded onto the Children's Committee of the World Blind Union (WBU), PVI was asked to attend the quadrennial Special Assembly of ICEVI. ICEVI stands for the 'International Council of Educators of the Vision Impaired Learner.

Upon arrival in London, I was greeted with freezing temperatures, and snow which later froze over. The big freeze has been well reported in the media. What was not reported was the beauty of the snow, of the Christmas lights in trees with snow nestling amongst the branches - all very pretty.

#### **Thursday, 2<sup>nd</sup> Dec 2010 RNIB, London:**

All meetings took place at the **R**oyal **N**ational **I**nstitute for the **B**lind = RNIB. I joined the meeting at afternoon tea where the Executive members were discussing the merits of not holding a 4 yearly World Conference and the merits of aligning the ICEVI quadrennial cycle to that of the World Blind Unions quadrennial cycle = WBU.

Discussions included the following points:

- The staging of a world conference was becoming cost prohibitive to ICEVI.
- The world conference was thought to be elitist.
- The world conference was only for those who could afford to attend?
- Should ICEVI provide conferences of a more regional nature thus reducing costs and making it easier for those developing countries to attend?
- That the Executive could continue to meet every 4 years to ensure the constitutional requirements of ICEVI are met (as we have done in London).
- By aligning ICEVI quadrennial cycle with the WBU this could create opportunities whereby ICEVI and WBU might wish to collaborate. I felt ICEVI was very keen to work more closely with WBU and vice versa. (Very much about working smarter.)
- Discussion, albeit brief, took place with regard to the Executive positions up for re-election and explanations of who was standing down etc and

why... This ensured everyone knew what was going on prior to the elections programmed to take place on the 3<sup>rd</sup> December, 2010.

The outgoing Chair explained that he would be standing down, because constitutionally he had to. He also explained why he thought that by having Lord Colin Low at the helm, ICEVI might well be able to further progress its global goals.

Discussion then occurred around the visit to the House of Lords later in the day. We were all invited to attend a reception at the River Room hosted by Lord Colin Low. Dress mode was suit and tie for men, business dress for ladies.

With the completion of discussions, the day finished whereby we all gathered to taxi to the House of Lords..... much excitement, everyone well dressed and well wrapped up such were the bitter cold temperatures.



Paul with a couple from Denmark at the House of Lords, London. Guess who is a very chuffed!

#### **Friday 3<sup>rd</sup> Dec RNIB London**

The day began with my walking with Penny Harten and guide dog from our Hotel to the RNIB. Penny is the CEO of the WBU. Due to the frost on the snow, walking was a tad dangerous, especially if your guide dog was out of its normal routine. This was also a very good way to get to know Penny.... We got on well. Penny spoke of the need to provide more family centred programmes when working with developing countries. I naturally agreed, adding that if you work in isolation of the family, and in particular of the parents, then programmes are likely to fail. Clearly, we were on the same page. She asked how we work in NZ when advocating.



## PVI NZ model respected internationally (continued)

I explained that consumerism is very strong in NZ, and that we are very appreciative to have the financial support of the RNZFB. Together with the RNZFB and the teachers of BLENNZ, we have been able to achieve considerable gains. Clearly a well organised parent movement helps when advocating with Government for improved services for our children. Penny listened and was clearly taken by our approach. I sensed an understanding from her that may well prove fruitful for developing better parent networks on a global scale!

The afternoon discussions centred largely on why the Education for All – (Vision Impaired -EFA-VI) was not the success ICEVI thought it might be. I listened for as long as I could until I had to say something. I was sitting amongst the African nations' delegates. I spoke to the need to discontinue working with the learner in isolation of the family. I further explained that if we continue to work this way our well intentioned programmes will fail. Involve the family, involve the parents in particular, and our programmes will have more chance of success. If this occurs, then funding is also likely to improve. The support from the African nations who seemed to understand from where I was coming was not surprising. It was the same with many American people sitting close by. The room went quiet, briefly, and I thought gosh have I offended some.... Then bless her heart Frances Gentle from Australia chimed in, in full support of my work in the Pacific. That the Fiji model of how we achieved what we did should be looked at seriously. Perhaps our work in Fiji could be used as a template for working with developing nations?

At the end of the discussion, Lord Colin Low, our new President, moved a motion that stated the intent of ICEVI to work to establish the formation of parent support groups globally. I believe this motion was seconded by either Penny or the President from the WBU. This was one of only four motions moved, I believe..... This is excellent support! To think that our New Zealand model is being taken seriously is wonderful.

### Saturday 4<sup>th</sup> Dec 2010 - ICEVI Workshop

Saturday was workshop day. I had placed on the walls 18 laminated covers of PVI's "Vision" magazines. This gave a pictorial history of our existence and issues important to us. It helped. It added credibility.

I also attended a "Low Vision Toolkit" workshop. This workshop highlighted the work done by the Welsh RNIB with the production of a CD on how to support pupils with Low Vision. This is primarily aimed at teachers, but equally appropriate for parents to use. I have a copy! It is an excellent tool which I would like to use in "Vision" on a semi regular basis.

We were placed into four smaller groups as per our identified areas of expertise. The four groups were Programmes, Sustainability, Advocacy and Networking. Networking later merged with Advocacy. I was placed in the Advocacy group. The group consisted of, WBU representatives, Perkins School for the Blind and ONCE representatives and myself as the Parent voice. The role of advocacy can be different in many countries. What delighted me was as a group we all appeared to be on the same page of intent and how to get there. Relationships were a key element. This understanding augers well for future outcomes.

### Key Learning's for PVI (NZ) Inc:

- Pride of our model and the NZ way of collaboration
- Pride of the relationship with the RNZFB & BLENNZ
- New relationships with ICEVI and WBU members.
- The appointment of Lord Low might well prove to be a very politically astute move.

### RNIB Children's Services visit 6th & 7th Dec 2010:

#### Key Learning's:

- I learned that educational services for children are delivered by the local councils. There are 120 different councils in England with whom the RNIB staff has to deal! Sadly, that is 120 different interpretations as to the value of what is required around blindness education.
- The Government has ordered that services by councils be cut in an effort to cut Government spending, hence the fear from RNIB staff. Comments like, the most vulnerable will be hit first or hardest hit, and communities like the elderly, and People With Disabilities (PWD's) are bracing themselves. Sound familiar!
- There are 24,000 Blind, DeafBlind and Vision Impaired children in England. The RNIB and the NBCS, (National Blind Children's Society), can account for 10,000. They do not know where the other 14,000 children and their families are!
- There is no organised consumer voice on behalf of these children. There is no parent body like we have in NZ. Comments from many I met were we desperately need an organisation like you have in NZ... It is almost impossible for us as service delivery groups to advocate against Government.
- A clear message of— "Whatever you do in NZ, keep the voice of consumers alive and healthy. We look upon you with envy."
- I was saddened by what I witnessed, "Unless the major players invest in collaboration and consumerism I see services for children suffering.

Paul



## South Pacific Forum 13th /14th January, RIDBC, Sydney and SPEVI

I was invited to attend the second Pacific Forum organised by Francis Gentle as Chair of the ICEVI - Pacific Region. The forum took place over the 13th & 14th January at the impressive venue of the Royal Institute of Deaf and Blind Children, North Rocks, Sydney.

Having attended a previous Pacific Forum and having noted progress, I was excited with the outcomes that this Forum might present.

This time more Pacific Island representatives were attending. They were from:- The Island States of Micronesia, Palau, Papua New Guinea (known as PNG), Australia, New Zealand, Fiji, Tonga, Vanuatu, Kiribati, and the Solomon Islands. This was achieved by the generous support from OZ Aid.

Day one saw an impressive presentation from Frederick Miller who works for the Pacific Forum Secretariat who has the mandate from all the Pacific countries to develop an inclusive education framework for all of the Pacific. This is achieved as a result of international funding for disability awareness. The work of this Fijian secretariat is impressive; and its CEO is Seta Macanawai, a blind man who has been most supportive of my work in Fiji.

- Of the willingness of the Pacific Island nations to determine in their own right a disability inclusive policy for their disabled children at school.
- Of the intent to work with Parents in their respective countries to ensure more disabled children attend school and of course to help establish more parent support groups.

### SPEVI, Sydney

SPEVI stands for the 'South Pacific Educators of the Vision Impaired Learner'. This biennial conference was held 16th-21st January 2011. I was invited to attend and to give a presentation on the value of a Parent Support Group. I did and accordingly Australian states are keen to implement. The previously established National Parent Association in Australia has become defunct due to many reasons, primarily though a lack of support from the professional service providers. This hopefully is about to change.

My presentation consisted of our history as displayed with our Vision posters, our values, beliefs, and our collaborative way of working with both service providers and the Ministries of Education, Social Development and Health. I particularly focused on the special relationship we now have with the Ministry of Education and of how we are considered to be partners and together with other parts of the disability sector in NZ, have been able to positively influence the REVIEW of Special Education. At the end the presentation was greeted with warm response and many stayed on afterwards to further discuss.



Attendees photograph

Later in the day, we did a stock-take of services available to Blind, Deafblind and Vision Impaired Learners in the South Pacific, sadly it is not a pretty picture..... We here in NZ are very fortunate in comparison.

Day two saw much forward planning and the development of a draft strategic plan for each of the developing Pacific nations in attendance.....

I was impressed with the progress we made in two days.



Paul, seen here explaining the value of our Vision magazine and the work we do. I might point out there was more than one attendee, about 30 attended!



PVINZ



# Time To Rethink 'Social Contract'

**MEDIA RELEASE, 24 December, 2010**

The Government's concept of a „social contract“ that commits families to years of intensive caring for ill, disabled, and elderly loved ones is old-fashioned and does not reflect modern life, says Carers NZ.



The national peak body representing New Zealand's 420,000+ carers says everyone can expect to give or receive family support during their lives. But when significant, ongoing care is needed, there are limits to what „natural supports“ spouses, parents, and other family and whanau carers should be expected to provide.

Carers NZ CEO Laurie Hilsgen says it is not up to government alone to decide what constitutes its social contract with families, and what levels of natural support are fair.

“It has to be a partnership we all contribute to and agree on: families, government, the community, and employers.”

“Today we are living longer at home with significant health and disability needs. Pharmaceuticals and advanced medicine have lengthened our lives, but they have also lengthened the commitment carers make for loved ones with high needs. As a society we have to rethink our approach to community based care, and ask whether it is fair to exploit family carers as a free or cheap source of labour, often for years and years.”

Carers NZ made its comments in response to the Government's announcement that it will appeal last week's Family Caregivers decision, which mirrors a previous Human Rights Review Tribunal case which found that not recognising parents or immediate family members as paid caregivers is discriminatory and unjust.

**Carers NZ says the Government is wasting money and time on court battles, when addressing the significant caring issues raised by the nine families involved in the High Court case would be a better investment.**

**“It feels as though the Government thinks it is buying time by lodging appeal after appeal about these issues, when in fact it is causing misery for the nine families and many others by not acting decisively with progressive policy to support family carers.”**

Carers NZ is the Secretariat for the NZ Carers Alliance, a coalition of more than 40 national not for profits which support families with health and disability needs. The carer movement is preparing to launch its We Care! national awareness campaign, which will call for genuine progress for family caregivers. Ms Hilsgen says the campaign will be directed at the Prime Minister, John Key, as caring affects every New Zealand family, employers, and the economy.

“Mr Key has described carers as unsung heroes. We are relying on his leadership to ensure his Government genuinely supports carers, and values their contributions to family life and society.”

**CONTACT** Laurie Hilsgen, 021 702 922 [info@carers.net.nz](mailto:info@carers.net.nz) [www.carers.net.nz](http://www.carers.net.nz)

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## **Introducing the New Model for supporting disabled people 17 December 2010**

Disability Support Services of the Ministry of Health has released a new model of how people with disabilities will be encouraged to be funded in the future. It is very much an empowerment model of people with disabilities having greater say in service provision and the funding allocation in terms of dollars not services. To clarify, currently we get assessed for services. In the new model we will get assessed in dollar terms. Very much acknowledging feedback from the sector this model also highlights Individualised Funding as the preferred option, further placing PWD in control should that be their wish. There is a trial in the Western bay of Plenty/Tauranga and is being run-out under the umbrella of Inclusion Aotearoa [www.inclusionaotearoa.co.nz](http://www.inclusionaotearoa.co.nz) or follow the link below.

To read the document in pdf format see the link below:

[http://www.moh.govt.nz/moh.nsf/pagesmh/10082/\\$File/new-model-presentation-17dec.pdf](http://www.moh.govt.nz/moh.nsf/pagesmh/10082/$File/new-model-presentation-17dec.pdf)



## When it doesn't pay to care! By [Catherine Masters](#) of the New Zealand Herald

Seventy-four-year-old Cliff Robinson arrived at the Auckland High Court on Monday.

He'd driven up from Thames with Marita, his 43-year-old daughter, who had put on some lipstick, painted her nails and was carrying a little black handbag for the big day. Her brother Johnny, 41, had to stay behind in day care because he has the potential to get quite rowdy and spin out of control, but Marita sat quietly next to her dad, or daddy as she still calls him, in the row of seats at the back of Court 8. She looked as if she was hanging on to every word of the complex legal arguments being outlined by the Crown but in reality she didn't understand any of it. She has microcephaly (a neurodevelopmental disorder) and at lunch she accidentally tipped a drink in her handbag, though she seemed pretty upbeat when she mentioned this. She'd been to the IHC ball in Tauranga, she'd said, eyes shining, where she had danced the night away.

Back in court, every now and then her dad Cliff would sigh, rub his eyes or mutter at what he was hearing, as did Peter Humphreys who was sitting a few seats along in the back row. Humphreys had also driven up from the Waikato but he didn't bring his daughter. Sian, 22, has Angelman Syndrome, a genetic disorder affecting the nervous system and causing a range of problems including serious developmental issues. She is a strong young woman and her behaviour is full-on.

The Robinsons and the Humphries are two of seven families who in January won a landmark case in the Human Rights Review Tribunal, only to find themselves shunted to this higher court where the win and its implications are being contested by the State. During the hearing back in 2008, the parents argued Ministry of Health policy prohibiting them from being paid to perform the hours of care their adult children had been assessed as needing was discriminatory because the ministry was happy to pay strangers to come into their homes and perform those hours of care. They argued some of the care their adult children required was extremely intimate and the standard of caregivers they had been sent, one after the other, was so dubious they preferred to do it themselves. The case was also about the freedom of choice for some of the adult children who wished their parents to be their caregivers and thus be paid the money allocated for their care. **The families won hands down and were elated.**

Disappointment soon followed when the Crown announced it would appeal and that case is now underway in the High Court. The Crown says the Tribunal made manifest legal and factual errors and that a lot more is at stake than these seven families. There are huge fiscal implications, they say. The Ministry of Health would have to change its whole framework of disability support services and the cost could be up to up to \$593 million a year because of all the family members who would come forward, and there would be other flow-on effects. The Office of Human Rights Proceedings, however, estimated the costs would only be \$32 to \$64 million because very few parents or family members would be willing or able to provide the very high level of care these adult children require.

In court either Judge Raynor Asher or the two lay people sitting alongside him from the Human Rights Review Tribunal - Jacquie Grant, a high-profile transsexual once dubbed the West Coast's much-loved "Tranny Granny" and Patsi Davies of Hamilton - would often ask questions of Crown lawyer Martha Coleman. Coleman explained the Ministry's argument that a social contract existed where people look after their own, and pointed out the policy in question was about filling gaps in services for people with disabilities. It was not about providing a wage for families - that was the business of the Ministry of Social Policy. For families who opt out of that social contract, for whatever reason, the state pays for the services to fill those gaps. But it does not pay when a parent, spouse or other resident family member wants to care for the person themselves. "The policies themselves, the schemes themselves, are designed to provide services, they're not an employment scheme for family pay to care Cliff Robinson with his intellectually disabled children Johnny and Marita, who he cares for full-time, at their home in Thames. Picture / Natalie Slade If families could be paid to provide care many would ask to be paid for the support they now provide purely out of love and affection. Crown lawyer Martha Coleman members, and that would be to change completely the nature of the scheme away from what it is..." People are rational human beings who would respond to economic incentives, she said.

The Ministry has to operate on a budget, and fiscal sustainability was an issue. If families could be paid to





## When it doesn't pay to care! (Continued)

provide care many would ask to be paid for the support they now provided purely out of love and affection, she said. Another issue raised was the risk families would become financially reliant on the income, which could impact on the independence of the disabled person. She said the system was a good one and key services existed to fill the gaps.

Outside court, Cliff Robinson had said how rosy they make the system sound, to which Peter Humphreys had laughed ironically and said "yeah, I want some of that". His family has tried many services which have not worked for Sian and he despairs at the quality of caregivers she has been sent. They are so low paid and anyone can walk in off the street and get a job, he says. In his affidavit to the previous Tribunal hearing, Humphreys wrote about a particular incident which had caused distress. An agency had sent a small, thin woman with a hat and glasses. "I turned my back for a moment and turned back to see her lying on the floor with Sian on top of her trying to remove her glasses... [Sian doesn't like glasses] "I reflected overnight and decided I couldn't cope with the anxiety and responsibility of trying to protect the safety of the carer while she was supposed to do the caring."

Jean and Stuart Burnett arrived at court on Tuesday. Stuart made a bit of an entrance. A trolley and chairs had to be moved out the way as he slowly but deftly parked his motorised wheelchair under a table at the back. Stuart, who has cerebral palsy and has very limited movement but a keen intelligence, is also a plaintiff in the case. He wants his mother as his paid caregiver - this is his choice, he says. In his affidavit to the Tribunal, he had explained his views on residential care. "Though the resident's basic personal and hygiene needs are met - their other needs as human beings are sometimes neglected, from my observation... "They seem to lead restricted, stifled lives with a loss of control over their own situation. This is not a choice that I would want to make for myself." And in his home, which he half owns with his mother, when cared for by contracted caregivers, he said this: "I have disliked the experience because often I have sensed that they cannot cope with my disabilities". His mother Jean is the oldest plaintiff. She is 76 now and has cared for Stuart for more than 40 years. She knows his body language - she can read him, understand him. Outside the court

room, when she was talking about the transient and intrusive nature of the caregivers who have been through their own home, Stuart, who can't speak, lifted his arm to his throat. Jean immediately translated: he was trying to indicate the case in the news recently about a caregiver who slit the throat of a tetraplegic. That case might be extreme but the point is Stuart is very vulnerable, Jean says. Not only can he be taken advantage of but he can easily choke and die if not fed properly because of his swallowing difficulties. She won't give up this battle for what she sees as justice until she's in a box, she says.

Life at the moment, though, is about putting one foot in front of another and hoping the van doesn't get towed from the three hour disability park near the Court. "[We're] trying to keep other people's rules, and it's impossible because they don't fit us." This case was brought under a section of the Human Rights Acts which allows citizens to challenge the Government on policies which may breach human rights. It is the first such case to go to the High Court but regardless of who wins, it can be appealed again and could go back to the Court of Appeal and then the Supreme Court, which could take years.

One of the original plaintiffs died in the time the case took to get to the Tribunal hearing. The case continues next week.

### **JEAN AND STUART BURNETT aged 76 and 44**

\* Jean has cared for Stuart, who has spastic atrophic cerebral palsy, all his life.

**"I have never allowed him to become a professional wall-starer ... Stuart does not just need someone to wash, feed and toilet him ... he also needs someone who can enable him to live his life and live his dreams."**

Jean Burnett

### **CLIFF, MARITA AND JOHNNY ROBINSON aged 74, 43 and 41**

\* The children both have intellectual disabilities. Johnny also has schizophrenia and diabetes.

\* When in care, Johnny needs two staff members all the time.

\* Cliff took the children out of homes when they were toddlers and has cared for them ever since.



**"What would cost the Government less — paying parents as caregivers, or meeting the cost of institutional care full-time for their children?"**

Cliff Robinson

### **PETER AND SIAN HUMPHRIES**

\* Sian, 22, was born with Angelman Syndrome and has very high disability support needs.

\* Peter has tried many caregivers but has experienced years of frustration.

**"I can't get my head around why the Government has to make our lives that much harder. They cannot provide an adequate system of regular personal care for Sian - it just isn't there."**

Peter Humphries.

### **GILLIAN BANS GROVE AND (DAUGHTER) JESSIE RAINE**

\* Jessie, 26, has spina bifida, is partially paralysed and has other disabilities. She has very high support needs.

**"I made my views known to the agency about their proposed plan to provide a team of caregivers for me ... I did not want that arrangement. It only lasted two weeks before I had an accident. I do not want strangers looking at my body - the care I need is intimate and I want some control over who provides it."**

Jessie Raine

*Quotes from affidavits presented to the original Human Rights Review Tribunal*

### **PVI Response:**

PVI has long championed for improved policies that better address the needs of the unpaid carer for parents such as us. This is why we were involved in the formation and introduction of the New Zealand Carers Strategy.

We believe that the above story highlights so many breaches of human rights that the Government will have no choice but to address this issue. This might well become an election campaign issue if this National led Government continues to drag its feet and fails to acknowledge and better support parents who are raising children with disabilities!

### **Low Vision Prevalence Data**

Low vision affects more than 2 million Americans and ranks behind only arthritis and heart disease as the reason for impaired daily functioning in Americans over the age of 70.<sup>1</sup> Low vision is defined as a visual impairment that is not corrected by standard eyeglasses, contact lenses, medication, or surgery and that interferes with the ability to perform everyday activities. It is most commonly described in terms of remaining visual acuity (central vision) and visual field, peripheral, or side vision.<sup>2</sup> Loss in central vision causes difficulty in detail discrimination (e.g., reading and discriminating fine detail and colour). Peripheral vision loss causes orientation and mobility problems, such as having difficulty seeing curbs/steps or difficulty seeing in lowlight conditions.

Baseline data from the 2002 National Health Interview Survey (NHIS) indicate that approximately 14 per 1,000 Americans aged 18 and older with a visual impairment use vision rehabilitation services. According to the same study, 22 percent of people aged 18 and older with visual impairments use visual and adaptive devices. <http://www.nei.nih.gov/nehep/programs/lowvision/index.asp>

Imagine if New Zealand had the above information and then the political will to do something about it. For many years PVI has had concerns regarding the overall eye health of New Zealanders. We have concerns that only the very serious cases are seen in our public system, the length of time on waiting lists often make sight loss conditions worse. Immense pressure exist upon families to take out expensive medical insurance so their child or loved one does not have to wait. Sadly this is becoming the norm rather than the public health system providing.

So we ask what happens to those who cannot afford expensive health insurance? What happens to those children who might have a moderate sight loss condition but will never be seen in the public system? Will their condition become more severe as a result of lack of timely intervention and how will that child achieve at school?

Do we understand the state of eye health in NZ? If not, why not?



## **Review of RNZFB Orientation and Mobility Children's Services are delivered**

The Ministry of Education is reviewing the way orientation and mobility services are delivered. These are the services provided to blind and low vision children to help them develop:

- the skills they need for independent travel and the concepts that underlie spatial reasoning and navigation
- skills usually developed through observation eg time monitoring, money management and organisation.

### **Why the review**

Currently these services are being delivered through a number of contracts for students who have moderate vision impairment or are ORRS verified blind and low vision students. The Ministry is seeking advice on how to improve orientation and mobility services to students in all parts of New Zealand.

### **What the review will consider**

In considering alternative ways to deliver the orientation and mobility services, the review will look at:

- the scope of orientation and mobility services
- different service components that are required to meet orientation and mobility needs in today's world
- the need for these services
- the evidence on how to best meet the orientation and mobility needs of children and young people
- the range and options for providing sustainable services and service models
- the implication of options for Maori and Pasifika students
- transition issues from early childhood services
- the skill requirements and workforce development implications of the options.

### **How the review will be carried out**

The Ministry has contracted Cognition Education to carry out the review. The review is being led by Dr Barbara Disley, Principal Consultant, Cognition Education Ltd. Barbara is being supported by an advisory group that includes: Chris Shelton (RNZFB); Teresa Bradfield (RNZFB); Veta Endermann (RNZFB); Stephen Bellamy (BLENNZ); Jane Wells (BLENNZ); Kay Daly (Moving Forward);

Paul Manning (PVI); Carin Sundstedt (Ministry of Education) and Yvonne Hope (Ministry of Education). The advisory group will provide advice on and have input into the review plan and will support the reviewer by providing information on current service provision and best practice. The advisory group will have the opportunity to canvas ideas and options and provide input into the final report. The advisory group will also provide input into the literature review and identify key people who can contribute information to the review.

### **Timeframes**

The review will be completed by the end of April 2011.

The review will be available on the Ministry of Education's web site from the end of May 2011. The Ministry will use the review to inform the way services to blind and low vision children are contracted and provided. If necessary the Ministry will make recommendations to the Minister of Education for changes to the way services can be provided.

### **PVI Response**

For many years, now Orientation and Mobility services for our children have been the "elephant in the room". We have been aware that many of our children's needs have continually failed to be met.

The reasons are many and varied and I will not go into them here. What I wish to state is, "The review Advisory Group (of which PVI is a part) is determined to look for a better way to provide services. Naturally, we have been advised there is no new money, that we must make do with what funding we have. This places pressure upon the Advisory Group and its leader, Barbara Disley, to look at new models of delivery. If we look at new models, and then decide that the model we currently have would work if funded appropriately; what then?

PVI believes that, while we respect the need to clarify service delivery models first before asking for more funding, the door should not be closed to increased levels of funding. Remember this is an election year and the Orientation and Mobility needs of our Blind, DeafBlind and Vision Impaired children must be better met.

With the correct political-will, funding will be available!



**PVINZ**



# 10 Tips for Parent Advocacy

By Pat Howie, Advocate from the Wrightslaw website [www.wrightslaw.com](http://www.wrightslaw.com)

## 1. Good advocates facilitate the IEP process.

Advocates must set an example for the entire IEP Team. They must be a role model of behaviour for the parent. Challenging school experts, demeaning school staff, or being inconsiderate or impolite, will not advance the child's cause. Your goal is to get better school services for the child. Good advocates ask questions and make valuable suggestions to advocate for a child. It is okay to disagree. It is not okay to put down or verbally attack someone.

## 2. Good advocates know the child and understand the disability.

Do your homework before you attempt to advocate for the child. Research the child's disability. Be ready with ideas about instructional methods that are research-based and peer-reviewed. Meet the child and the family in the home environment. Put off making recommendations until you fully understand how the child's disability affects his or her life and education.

## 3. Good advocates try to reduce existing barriers between the parent and the school.

Your goal is to bring the school and the parent closer to agreement. Good advocates explain to parents that negotiation is part of the IEP Team process – and a part of life! Pouring gasoline on a fire ensures that everyone gets burned and does not improve the child's lot.

## 4. Good advocates are willing to admit mistakes and to apologize.

No one is perfect. We all make mistakes. Good advocates are not afraid to say they are sorry when they make a mistake. They may even write a note to everyone involved, apologizing and asking for forgiveness.

## 5. Good advocates hone their listening skills to a fine edge.

You must learn to listen to everything that others say. Sometimes, what others do not say is most important. If you are not listening, you may not hear what others say and what they do not say. Good advocates repeat and paraphrase what they have heard to avoid misunderstandings. They ask others to verify that they understood correctly. Good advocates ask follow-up questions. They do not interrupt even when they are faced with rudeness and discourtesy.

## 6. Good advocates learn the art of negotiation.

Remember the old saying, "You catch more flies with honey than you do with vinegar?" Learning to negotiate is not a sign of weakness or that the parent's position is not valid. Negotiation is an art that good advocates polish to a fine finish. Successful negotiations allow everyone to come out of the IEP Team Meeting feeling like winners. Brice Palmer, noted advocate from

Vermont, says it best: "Good advocates learn to develop a language of persuasion rather than a language of positional combat."

## 7. Good advocates understand special and general education law and the interrelationship between these and other laws.

The law is not a static entity. It changes every day through court decisions and other types of clarifications. Good advocates review special education law often. They know that answers to frequently asked special education questions may be found in other unrelated laws. For example, Department of Agriculture regulations address special dietary requirements for children. A State's Department of Health regulations may address classroom size, lighting, and window light. General education law may provide insight into class size and case load issues. The U.S. Justice Department provides guidance on bullying and harassment.

Good advocates understand that school policies often omit the special needs of students with disabilities. School emergency plans may not address the needs of children in wheelchairs or children who are deaf or blind. Good advocates learn to research many different laws.

## 8. Good advocates know that understanding the law is different from quoting the law.

Good advocates know the law but they understand that it is often ineffective and counterproductive to quote it. Pete Wright once said, "[A] parent should never quote law, it simply polarizes relationships, instead seek 'help' in better understanding something best left to rocket scientists and lawyers.

## 9. Good advocates understand the importance of ethical behaviour in their practice.

There is no Code of Ethics or Professional Responsibility for special education advocates. Advocates have nothing to look to for guidance and there is no governing body to oversee their practice. There are no penalties for advocates who act unprofessionally or unethically. This does not suggest that advocates should disregard ethics and engage in irresponsible behaviour. Good advocates understand that the professional respect of the IEP Team is a key to successfully assisting parents achieve an appropriate education for their child.

## 10. Good advocates treat others the way they would like to be treated.

No one likes surprises. Members of IEP Teams do not respect or trust advocates who drop bombshells. Taking the team by surprise is likely to backfire, especially if the team "captain" is a gatekeeper or is determined to be the one who runs the show. Making the IEP Team Meeting a war of wits does not benefit the child nor does it facilitate the process for the parents.



PVINZ

## Jillian Applegate RNZFB Child and Family Worker, Napier

**Jillian Applegate** a Child and Family Worker based in Napier has sadly resigned. Jillian had been supporting families and children for many years and made a very positive impact with all she worked with. We are saddened to see Jillian go, however she goes with our blessings.....

Jillian thanks for all your aroha, the families and their children will miss you.

These pictures captures Jillian's spirit perfectly...





## Did you Know?

### Variety Scholarships:

**For further information on application criteria or to download an application form, please go to [www.variety.org.nz](http://www.variety.org.nz) or call**

**Heather Stevens on (09) 520 4111.**

### Payroll Giving for PVI

**Payroll Giving:** - Is a relatively new initiative that enables you to be able to donate straight from your pay and receive an immediate tax credit. That is:

33 cents for each \$1.00 donated is tax deductible. Therefore, if you donate \$10.00 per pay period, \$3.30 is then deducted from your PAYE. The result is a total cost to you of only \$6.70. It is up to your employer to decide if they wish to offer you the scheme or not. If your employer offers payroll giving then you can choose to donate. Our perspective at present is to seek a small donation of say \$5.00 per pay period at a net cost to you of \$3.35. We believe this is the best way to attract long term financial supporters. *PVI is an approved donee organisation on the IRD website.*

We take this opportunity to seek support from our parent and wider communities. This is our new reality, we can no longer rely on the RNZFB charity dollar as PVI's primary funder.

PVI has positioned itself as a credible charity (Charity Commission number CC 20913) and to this end

we ask that you support the Charity of PVI ..... alongside any other charity.

What will donated monies be spent on and how will this affect the parents and children of PVI...

- Regional training/development
- Advocacy
- The PVI Conference
- The Vision Magazine

**Considering the impressive gains PVI have achieved of recent years, the continued funding cuts as recommended by the RNZFB Board of Directors are a bitter pill to swallow.**

- Parents, your support is needed urgently.
- Talk to your work colleagues, encourage them to donate,
- Talk to your wider family/whanau etc.

### **RNZFB Performing Arts Camp**

Come and be part of a camp that will focus on performance, dance, drama, and music! You will get to explore behind the scenes of theatres, studios and workshops. You will receive tuition from some of Wellington's expertise teachers! At the end of the week you will be given the opportunity to present a performance showing off the skills, techniques and knowledge learnt throughout the camp.

You may also have chance to attend a live musical theatre show during the week!

**When:** Tuesday 26<sup>th</sup> April – Friday 29<sup>th</sup> April

**Where:** Wellington City – the arts and culture capital of NZ! The programme will be based at the RNZFB Wellington Office. Accommodation will be Rowena's Lodge, Mt Victoria which is handy to amenities and public transport

**Who:** Blind and Vision Impaired 12 – 18 year old RNZFB Members from around New Zealand who are interested in Performing Arts. Participants must be independent in terms of self care.

**Cost:** The Subsidised Fee is \$150 per member. This includes transport, meal, accommodation, and activity costs.

***If you would like more information please contact:***

**Sarah Jones  
Recreation Advisor  
RNZFB Christchurch  
03 375 4327  
027 212 6321  
[sjones@rnzfb.org.nz](mailto:sjones@rnzfb.org.nz)**

**APPLICATIONS CLOSE FRIDAY 18<sup>th</sup> MARCH!  
BE IN QUICK! LIMITED PLACES NO LATE  
APPLICATIONS WILL BE ACCEPTED**

***"Never doubt that a small group of  
committed  
citizens can change the world. Indeed it  
is the only thing that ever has".  
Margaret Mead.***





**www.pvi.org.nz** This is our website, check it out!

**www.blennz.org.nz** The new BLENNZ website, take a look, well worth the journey!

**www.kapomaori.com** The official website of Ngati Kapo Aotearoa Inc

**www.abcnz.org.nz** The largest Blind Consumer group in N.Z. An excellent website.

**www.humanware.com** Excellent products available for both Low Vision and Blind users.

**www.pacificvision.org.nz** This website has links to many international providers of Low Vision aids.

**www.biopicdriving.org** This website explains how some low vision people can gain extra vision by using bioptic lens that in some cases enables them to drive legally!

**www.aniridia.net:** Anidiria Foundation International.

**www.aniridia.org:** Anidiria support

**www.albinism.org.nz** New Zealand's website for those wishing to know more about Albinism.

**www.nzord.org.nz** This website has links to many international sites containing information concerning rare disorders. This site is the New Zealand link.

**www.rnzfb.org.nz** The website of the Royal New Zealand Foundation of the Blind.

**www.quantech.com.au** This website has good information on new Mountbatten training resources. Worth visiting if your child uses braille.

**www.tsbvi.edu** The Texas School for the Blind and Vision is a leading educational facility. Excellent information and links to other places.

**www.minedu.govt.nz** The official Ministry of Education website. Good information, easy to use.

**www.varietyclub.org.nz** The Variety Club may be able to provide financial assistance for children with special needs. I have found them most supportive and helpful in the past. Contact 09 522 3743.

**www.parent2parent.org.nz** Parent 2 Parent is a nationwide support group of parents who have children with special needs.

**www.carers.net.nz** This is the official website of Carers NZ. This website has excellent information on a range of carers needs. They produce an excellent magazine called "Family Care". This magazine is free to all carers, just ring Sara at 09 406 0412 or email: info@carers.net.nz

**www.napvi.org** The National Association of Parents of Vision Impaired USA. This is a very good website, note the section re parent matching etc.

**www.cpsociety.org.nz** NZ's Cerebral Palsy site an excellent website, very informative and easy to use.

**www.wrightslaw.com** An excellent website for tips on IEP's, it is USA based where laws are different, the tips and ideas are very similar.

**www.zabonne.com** Zabonne's website hosted by Ivan Pivac, much information regarding blind and low vision aids, plus technology aids for children with additional disabilities.

**www.maparentsupport.com:** - a web site for parents to find support from others who have children with Microphthalmia Anophthalmia.

**www.familytimes.co.nz** a newspaper produced quarterly, ChCh and Auck based, well worth a read.

**RNZFB Holiday Home:** The RNZFB have one Holiday Home available to rent for members. It is located in Tauranga at \$50.00 per night. For further information contact Karen at the Tauranga RNZFB Office between 9.00am and 12.00noon on 07 578 2376.

**The Koru Care:** This charity is linked to Air New Zealand. They specialise in taking children with Special Needs to Disneyland/Gold Coast Australia.

**Contact 09 523 2456** to see if your child qualifies.

There are also contacts at Wellington and Christchurch offices of Air New Zealand.

A CD called "**A Family Affair**", available from BLENNZ Homai Campus, **09 2667109** it gives good information re the National Assessment Services available at BLENNZ.

**PacificVision** : email Barry at **barry@pacificvision.org.nz** excellent low vision equipment.

**Parents: - Feel free to write to the following Members of Parliament the good news or bad news concerning either your child's needs or yours as a parent!**

**Prime Minister** = pm@ministers.govt.nz

**Minister of Education** atolley@ministers.govt.nz

**Minister of Disability Issues** tturia@ministers.govt.nz

**Minister Maori & Assoc Min Education** psharples@ministers.govt.nz

### **PVI Regional Support Vacancies:**

**We need more parents to volunteer as Regional Representatives in the following areas: - Northland, Especially Auckland, Waikato, Taranaki, Palmerston North, Dunedin and Southland.** We need more parents acting as signposts to support other parents in your community. We wish to create teams within your own community hence sharing the workload. National Training is provided FREE normally 1 weekend per year. Support seminars will more than likely be provided in a community near where you live. If you have the time to give and wish to further support us please contact Paul: **0800 312 019**



## Your PVI Board

### Chair: Lower North Island Representative:

Mr. Kevin Beaver: 04 589 3719 k.beaver@clear.net.nz

### Upper S.I. Representative:

Mr. Grant Davies: 03 326 4013

dandgdavies@xtra.co.nz

### Treasurer: Central N.I. Representative:

Mr. D Fairgray: 027 286 7798

### Lower South Island Representative:

Ms. Judith Hyslop: 03 467 5774:judithhyslop@xtra.co.nz

### Upper North Island Representatives:

Mrs. Kim Lewin: 094221012 lewinfamily@xtra.co.nz

Mr. K. Singh: 027 320 6317 kam\_mit@hotmail.com

### Anywhere in N.Z. Representative:

Mrs. Dionne Gilligan: 06 344 7755 dionnesg@gmail.com

### Tangata Whenua Representatives:

Ms. Riripeti Paine: 06 838 3949

Mrs. Kitty Tuari: 09 372 5453 ktuari@gmail.com

### Pacific Island Representative: Vacant

### PVI's Whakatauki/Proverb:

*Kia hora te marino, Kia whakapapa paonamu te moana, Kia tere te karohirohi, I mua I te haerenga, Kia tau te rangi-marie. May the calm always be at your side, May the Sea glisten like pounamu May the summer shimmer, dance across your path, May you always find peace.*

### Return Address:

Parents of Vision Impaired NZ Inc

PO Box 366

Waikato Mail Centre

Hamilton 3240



## Regional Support Parent Contacts

**Dargaville:** Gaynor Edgar 09 439 4439

**Wellsford:** Kim Lewin 09 422 1012

**AuckNorth Harbour:** Linda Moore-Carter 09 442 133

**Auck. Central:** Vacancy please apply

**Auck. South:** Kawaljeet Singh 09 299 8028

**Auck. West:** Paulette & Rodney Francis 09 835 1232

**Auck. East:** Kawaljeet Singh 09 299 8028

Tirzah Shepherd 09 530 9539

**Hamilton:** Maxine Jeffery 07 853 7006

**Tauranga:** Linda & Don Fairgray 027 286 7798

**Rotorua:** Lex & Helen Craig 07 349 3191

**Wairoa:** Riripeti Paine 06 838 3949

**Napier:** Lou Halbert 06 845 4706

**Taranaki:** Vacancy please Apply

**Wanganui:** Dionne Gilligan 06 344 7755

**Manawatu:** Vacancy please apply

**Wellington:** Christine Pask 04 527 7585

David and Rhonda Heather 04 203 6539

**Nelson:** Adrian Secker 027 201 1028

Trudy Perrett 03 544 6641

Mandy Blades 03 545 8501

**Christchurch:** Andrea Lamont 03 980 1566

**Oamaru:** Pat Fox 03 434 3499

**Alexandra** Sarah Hinton 03 449 2414

**Invercargill:** Kim Hartley 03 217 1906

**Regional Support Parent Training kindly financed by the J R McKenzie Trust**